Confabulation in Individuals with Disorders of the Corpus Callosum: Educational Implications

Cheryl Lynn Wright
Western Kentucky University, cheryl.wright689@topper.wku.edu
CONFABULATION IN INDIVIDUALS WITH DISORDERS OF THE CORPUS CALLOSUM: EDUCATIONAL IMPLICATIONS

A Dissertation
Presented to
The Faculty of the Educational Leadership Doctoral Program
Western Kentucky University
Bowling Green, Kentucky

In Partial Fulfillment
Of the Requirements for the Degree
Doctor of Education

By
Cheryl Lynn Wright

December 2017
CONfabulation in individuals with disorders of the corpus callosum: educational implications

Date Recommended

Aaron Hughey, Director of Dissertation

Monica Burke

Karl Laves

Dean, Graduate School

Date
To my sweet Dulcinea.

I go into the world to exact glory and gather laurels, so

that I might lay them at your feet.
ACKNOWLEDGMENTS

I would like to express my deep appreciation and gratitude to my advisor, Dr. Aaron Hughey, for the patient guidance and mentorship he provided to me. Dr. Hughey’s intellectual heft is matched only by his genuine good nature. I am truly fortunate to have had the opportunity to work with him. I would also like to thank my committee members, Drs. Monica Burke and Karl Laves for the friendly guidance, thought-provoking suggestions, and the general collegiality that each of them offered to me. In a similar vein, I’d like to recognize Robert Cobb, Drs. Stephen Miller, Pamela Petty, Joseph Cangemi, and Tony Norman for the contributions that each of them made to my intellectual growth during my years of study at Western Kentucky University.

I was blessed beyond measure with an amazing, support system, the helpful office staff, Gaye Jolly Pearl, Wendi Kelley, and the WKU library staff. Deep gratitude to my tulpa Egbert B. Gebstadter and friend Michelle Edwards for keeping me on track.

I am continually amazed by the community of people associated with Disorders of the Corpus Callosum. Thank you for your participation and I hope this body of research can contribute in a positive way.

LouAnn, Nikolas, Lanta, and Andaman, thank you for allowing me time. Finally, I’d be remiss if I didn’t acknowledge the innumerable sacrifices made by my husband, William, in shouldering far more than his fair share of the parenting and household burdens while I pursued this final degree. Your love and support amazes me and I will forever be thankful for all you’ve given me.
CONTENTS

LIST OF TABLES ........................................................................................................................................ viii

ABSTRACT ................................................................................................................................................. ix

CHAPTER I: INTRODUCTION .................................................................................................................... 1

Research Problem .................................................................................................................................... 1

Purpose of the Study ................................................................................................................................ 1

Research Questions ................................................................................................................................. 2

Limitations ............................................................................................................................................... 3

Assumptions ............................................................................................................................................ 4

Definition of Terms ................................................................................................................................. 4

Organization of the Dissertation .............................................................................................................. 7

CHAPTER II: REVIEW OF LITERATURE .................................................................................................. 8

Disorders of the Corpus Callosum ........................................................................................................ 8

Historical Perspective ............................................................................................................................ 9

Associated Difficulties ........................................................................................................................... 9

Physical Co-Morbid Associations ........................................................................................................ 10

Behavioral Associations ....................................................................................................................... 11

Language Associations .......................................................................................................................... 12

Cognitive Associations .......................................................................................................................... 14

Confabulation ........................................................................................................................................ 16

Historical Perspective of Confabulation ............................................................................................... 16

Confabulation Classification ............................................................................................................... 17

Rating Scales for Confabulation ........................................................................................................... 17
Finding Related to the Literature .................................................................48
Implications ...............................................................................................49
Limitations ...............................................................................................49
Recommendations for Future Research .....................................................50
REFERENCES ............................................................................................51
APPENDIX A: IRB Approval ......................................................................65
APPENDIX B: Informed Consent Letter .....................................................66
APPENDIX C: Permission to Administer the Questionnaire at the Disorders of
the Corpus Callosum Conference .............................................................68
APPENDIX D: Trait Study Questionnaire ...................................................69
LIST OF TABLES

1. Interview Schedule.................................................................34
2. Reported Rate of Confabulation..............................................42
3. Age of Individual with DCC x Reported Rate of Confabulation........43
4. Gender of Individual with DCC x Confabulation Rate....................44
5. Spontaneous Confabulation in Individuals with DCC x
6. Self Reporting vs. Community Reporting.....................................45
Individuals with disorders of the corpus callosum (DCC) may have subtle cognitive differences. Historically, confabulation has been associated with DCC. Therapies to mitigate confabulation is a newly emerging field. This study explores the possible educational implications that those with DCC may experience with confabulation.

The community of people with DCC and the community of people who interact with individuals with DCC were surveyed to ascertain the prevalence of confabulation within the population of those with DCC. A subset of questions probed whether age and/or gender impact the rates of reported confabulation. The research paradigm included a section that covered the possible discrepancy between self-reporting of confabulation and incident reporting by others. Potential educational implications were explored and recorded.

Findings indicate that confabulation issues are a concern in the DCC community, specifically provoked confabulation issues as an educational concern. Confabulation occurs across the ages and is not gender specific. Individuals with DCC self-report incidences of confabulation at a lesser rate than the population who interact with people with DCC.
This investigation is foundational for the exploration of educational methods for mitigating confabulation. The specific population of individuals with DCC, and the community who interact with individuals with DCC, can benefit from educational best practices based on information from this research.
CHAPTER I: INTRODUCTION

Research Problem

The connectivity of the human brain endows it with complexity. The corpus callosum, the largest connective structure in the brain, is often referred to as the bridge between the brain’s hemispheres. In simple terms, it is the information superhighway between the left and right hemispheres. It is estimated that 1 in 4,000 people are born with a disorder of the corpus callosum (Paul et al., 2007). Disorders of the Corpus Callosum (DCC) is an encompassing definition that includes thinning of the corpus callosum, malformation, partial absence, acquired damage to the corpus callosum, as well as a complete absence of the corpus callosum connective structure. A variety of developmental, physical, behavioral, cognitive, and language difficulties are associated with DCC. Confabulation, or the telling of misinformation without deceitful intent or knowledge, is a symptom that is associated with DCC that has yet to be quantified.

Purpose of the Study

The purpose of this study is to examine the relationship, specifically educational implications, between confabulation and people with disorders of the corpus callosum. An analysis of how episodes of confabulation have impacted those connected with DCC has yet to be fully explored. This study invited the community of people associated with DCC to share their perceptions of the educational impacts of confabulation. Badaruddin et al. (2006) linked diagnostic criteria for autism, specifically social interaction and social communication traits, to some children with DCC. Individuals with DCC and those with autism have been described as giving the impression of social naivety, and meaningless or inaccurate conversations for a given situation despite normal fluency.
Schilmoeller and Paul (2003) recognized confabulation as an associated trait in individuals with DCC.

Kang’s (2008) dissertation entitled *Mental State Attribution in Agenesis of the Corpus Callosum Versus High Functioning Autism* indicates that individuals with DCC scored inaccurate, or incomplete, in their interpretation of language context and appropriateness. Studies in cognitive connectivity have suggested that integrating multiple sources of stimulation may be a common characteristic of Autism Spectrum Disorders (ASD) (Lefebvre, Beggio, Bourgeron, & Toro, 2015). Shobe (2014) created a framework from research in neuroscience, experimental psychology, clinical psychology, and evolutionary psychobiology that suggests:

…the involvement of each hemisphere is qualitatively different, occurring at different points or levels in processing of emotional stimuli, making very different contributions to emotional perception and experience, and for very different purposes (p. 1).

Scaife (2014) noted: “Confabulation is a scientifically documented phenomenon” (p. 471).

This dissertation is designed to add precision to the description of confabulation in persons with DCC. Attitudes toward educational implications also are recorded.

**Research Questions**

This study examines the following research questions.

1. What is the prevalence of confabulation within the community of individuals with DCC?
2. Does age affect rates of confabulation within the population with DCC?
3. Does gender affect rates of confabulation within the population with DCC?

4. Is there a discrepancy between self reporting of confabulation and incident reporting by others?

5. Has confabulation had an impact on education for the person with DCC?

**Limitations**

Although the number of callosal fibers is already fixed near birth, structural changes continue to occur after birth such as fiber myelination, redirection, and pruning (Luders, Thompson, & Toga, 2010). Recent studies of shape (Martin-Loeches, Bruner, de la Cuétara, & Colom, 2012) and size (Lefebvre et al., 2015) of corpus callosums have emphasized the need for further study to determine how differentiation of the corpus callosum affects cognitive performance.

A 2008 investigation of psychological vulnerabilities during interrogative interviews by North, Russell and Gudjonsson found that individuals with high-functioning ASD do not differ significantly from individuals in the general populous of similar intellect on the measure of interrogative suggestibility in terms of the extent to which they yield to misleading questions or change their answers following negative feedback. Studies of personality and behavior have indicated individuals with DCC may have poor self understanding (Brown & Paul, 2000). Individuals with DCC co-occurring with a diagnosis of autism show more difficulties and, extreme scores compared to comparison groups in self- referential and social cognition tests (Lombardo, Chakrabarti, Lai, MRC AIMS Consortium, & Baron-Cohen, 2012). Scaife, in his 2014 article on self-knowledge and confabulation, argued that “we should take skepticism about our self-knowledge more seriously” (p. 471). An unawareness that one has a
disability or limitation has been associated with confabulation (Feinberg & Roane, 1997; Hurlburt, & Schwitzgebel, 2007).

A high percentage of people with DCC display characteristic traits of individuals on the autism spectrum. Interrupted interhemispheric information transfer, served by the corpus callosum, is a primary contributor to the core autism traits (Lau et al., 2013). Individuals with DCC, similar to those with autism, lack insight into their cognitive and behavior difficulties. Parents of adult individuals with DCC and/or autism report their children as having a greater level of impairment than perceived by the respective adult child.

**Assumptions**

The assumptions of this dissertation include:

1. Individuals with DCC have reported incidents of confabulation.

2. Individuals with DCC self-report confabulation at a lesser rate than individuals who interact with them.

3. The effects of confabulation in the educational setting should be further researched.

**Definition of Terms**

The following terms are used within this study:

*Anosognosia*: An unawareness that one has a disability or limitation (Feinberg & Roane, 1997).

*Autism spectrum disorders (ASD)*: The criteria for diagnosing ASD is given in the DSM-5 and includes: “A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays and manifest by 3 of
3 symptoms”; “B. Restricted, repetitive patterns of behavior, interests, or activates as manifested by at least 2 of 4 symptoms”; “C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities);” and “D. Symptoms together limit and impair everyday functioning” (American Psychiatric Association, 2013).

Comorbid: “The presence of more than 1 distinct condition in an individual” (Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009).

Confabulation: A broad definition of confabulation is “the production of false or erroneous memories without the intent to deceive” (Chlebowski, Chung, Alao, & Pies, 2009).

Corpus callosum: “The largest connective structure in the brain. It consists of over 190 million axons that transfer information between the two cerebral hemispheres” (Paul et al., 2007).

Disorders of the corpus callosum (DCC): Currently, there is some variation in how callosal conditions may be described in medical reports and by medical providers. DCC includes dysgenesis, as well as other acquired damage to the corpus callosum (e.g., due to stroke). Below is a list of the most common terms used to describe these conditions. “Agenesis of the corpus callosum is a congenital (lifelong) brain abnormality that occurs when the corpus callosum does not develop as it should during the early prenatal period. It can occur as an isolated condition or in association with other brain abnormalities or physical or medical conditions.” “The types of callosal abnormality that occurs depends on the cause and timing of the disruption to prenatal brain development. If the corpus callosum does not form
during the prenatal period, it will not develop later (Department of Education & Human Development, 2008). Common clarifying subdivisions of disorders of the corpus callosum include but are not limited to:

(ACC) Agenesis of the corpus callosum: All or a portion of the corpus callosum is absent; this includes both complete and partial ACC.

(AgCC) Agenesis of the corpus callosum: All or a portion of the corpus callosum is absent. This acronym has appeared more recently in some research literature.

(c-ACC) Complete agenesis of the corpus callosum: The corpus callosum is completely absent.

(p-ACC) Partial agenesis of the corpus callosum: A portion of the corpus callosum is absent; most often it is the posterior (back) portion that is missing.

Hypogenesis of the corpus callosum: Another term sometimes used to describe partial ACC.

Hypoplasia of the corpus callosum: The corpus callosum is present, but is abnormally thin.

Dysgenesis of the corpus callosum: The corpus callosum is present but is malformed in some way; this includes p-ACC and Hypoplasia” (Department of Education & Human Development, 2008).

Provoked confabulation: “In momentary or provoked confabulation, fleeting intrusion errors or distortions arise in response to a challenge to memory, such as a memory test” (Kopelman, 2010, p. 15).
Spontaneous confabulation: “In spontaneous confabulation, there is a persistent, unprovoked outpouring of erroneous memories” (Kopelman, 2010, p. 15).

Organization of the Dissertation

This dissertation is divided into five chapters. Chapter I presented the purpose of the study and research questions, significance, limitations, and assumptions. Chapter II is a review of literature that illustrates the theoretical background and empirical foundation for this study. The methodology is explained in Chapter III. Chapter IV describes the results from the data analysis. Finally, the findings and implications of this study, as well as recommendations for future research, are discussed in Chapter V.
CHAPTER II: REVIEW OF THE LITERATURE

Disorders of the Corpus Callosum

The corpus callosum is the largest midline structure in the brain. Often it is referred to as a bridge between the two hemispheres of the brain. Disorders of the Corpus Callosum (DCC) can be diagnosed reliably and characterized in prenatal life (Volpe et al., 2006). As neuro-imaging becomes more common, the reported ratio of persons with corpus callosum disorders is becoming clearer. At present, the National Organization of Rare Disorders (NORD) estimates rates at 7 per 1,000 (National Organization of Rare Disorders, n.d.). DCC may be congenital, and the corpus callosum does not rebuild or repair after birth (Luders et al., 2010). Although many people with DCC are healthy, others have a wide range of medical and physical differences. Characteristics may include health related difficulties, physical differences, developmental delay, social/behavioral differences, and cognitive and communication challenges. Confabulation, communicating information that is untrue while perceiving it is true, is among the list of possible challenges for people with DCC.

DCC, like autism, is a spectrum disorder. People with DCC have a wide range of intelligence from gifted to intellectually impaired. A person with average to gifted intelligence and DCC may have subtle differences in the way they perceive and react. Research suggested that even individuals with isolated Agenesis of the Corpus Callosum (ACC) and normal intelligence may experience subtle neuropsychological and cognitive challenges. The implication that a person may have a perceivably normal IQ and yet have episodes of confabulation could have many personal, educational, and legal implications (Garven, Wood, Malpass, & Shaw, 1998; Roma, Sabatello, Verrastro
This dissertation investigates the educational implications between confabulation and DCC.

**Historical Perspective**

The corpus callosum is unique to placental mammals (Paul, 2010). Congenital agenesis of the corpus callosum was first acknowledged in 1812 when Reil published the first detailed report on this condition. In a study by Brown, Paul, Symington, and Dietrich (2004), it was noted that individuals with agenesis of the corpus callosum can, in some cases, perform in the normal range on standardized intelligence tests. Nevertheless, recent studies have suggested that individuals with ACC and normal IQ scores have deficits in domains of fluid and social intelligence (Brown, W. S., Anderson, L. B., Symington, M. F., & Paul, L. K. (2012). Anecdotal reports from families suggest deficits in the comprehension of jokes and stories and diminished appreciation of the subtleties of social interactions. Also in the Brown et al. (2004) study, individuals with ACC performed worse than controls on the narrative joke subtest.

**Associated Difficulties**

A variety of difficulties are associated with DCC, including developmental, physical, behavioral, cognitive, and language. When the corpus callosum develops between 8 and 20 weeks’ gestation, disturbed embryogenesis during this time period can lead to the complete or partial absence, or other abnormalities of the structure (Marszal et al., 2000). Congenital anomalies of the corpus callosum may be comorbid with other cerebral malformations (Sorensen, 1997). Although DCC can occur in isolation, the large majority of cases occur in conjunction with other abnormalities (Kaufman et al.,
Sauerwein and Lassonde (1994) found individuals born without a corpus callosum can have normal intelligence, but most of the patients test and tend to function at the low end of the normal range. Intellectual functioning may be still lower if other malformations of the nervous system coexist. DCC is a component of at least 28 genetically identifiable syndromes.

**Physical Co-Morbid Associations**

Congenital DCC may be clinically asymptomatic and occur as an isolated malformation discovered at autopsy or by neuroimaging. More often, it is associated with other developmental abnormalities, both within other organ systems and the central nervous system. Research by Wisniewski and Jeret (1994) recognized that congenital disorders of the corpus callosum are not an entity unto itself. In a study by Taylor and David (1998) examining 56 cases of agenesis of the corpus callosum in the United Kingdom, nearly two thirds had epilepsy, half of the adult cases had clinically estimated intellectual impairment, and a third a psychiatric disorder. Associated learning difficulties and epilepsy are commonly seen. The study by Jeret, Serur, Wisniewski, and Lubin, (1987) found Aicardi, acrocallosal, Andermann, and Shapiro syndromes are characterized by DCC, while others are only sporadically associated (e.g., fetal alcohol syndrome, Leigh disease, Dandy-Walker syndrome, Arnold-Chiari II syndrome). This study also found that in non-Aicardi patients, the male-to-female ratio was 3:2 and X-linked recessive inheritance is postulated to play a role in some cases. “Common abnormalities in acallosal patients included: mental retardation [sic] (MR), 85%; seizures, 42%; ocular anomalies, 42%; gyral abnormalities, 32%; hydrocephalus, 23%; other central nervous
system (CNS) lesions” (Jeret et al., 1987, p. 255). Abnormal patterns of corpus callosum morphology and shape may be implicated in Williams syndrome (Sampaio et al., 2012).

When compared with controls, ACC patients perform poorly in several tasks that require interhemispheric communication; however, some of the impairments are subtle. (Meerwaldt, 1983). Significant differences were found in tests of coordination and stereognosis both with ACC patients and callosotomy subjects (Joseph & Bannister, 2001; Meerwaldt, 1983). Results demonstrated that individuals with ACC have significantly greater difficulty reorienting attention to an invalidly cued target stimulus occurring in the opposite visual field (Dennis, 1976). Since congenital absence of the corpus callosum significantly reduces efficiency in the reorienting of attention between visual fields, spatial attention cannot be completely unified. The mobilization of attentional resources within each hemisphere must depend on callosal processes (Hines, Paul, & Brown, 2002, p. 1804).

Behavioral Associations

Paul’s 2010 discovery paper on developmental disorders with callosal involvement suggests that, in addition to the general cognitive effects of callosal malformation, callosal reduction has a unique behavioral impact on social skills and other forms of rapid problem solving in developmental disorders. The Párraga, Párraga, and Jensen (2003) study underscored the importance of conducting a comprehensive neuropsychiatric evaluation in children with severe behavior problems and other confusing symptoms.

Parents of children with DCC commonly report it is difficult to know at any moment what their child is feeling or experiencing emotionally. Researchers in the field
of DCC have defined the hapax “alexithymia” as “no words for feelings and moods” (O’Brien, 1994). Common characteristics of alexithymia include lack of emotional expressiveness, poor fantasy life, concrete thought, feelings based on external events, and a tendency toward somatic complaints (Brown & Paul, 2000; Lesser, 1981; Nemia & Sifnoes; Paul (2004); 1970; Sifneos, 1972; Sifnoes, 1973). Agenesis of the corpus callosum (AgCC) is a congenital disorder that can have significant effects on social and emotional behaviors, including alexithymia, difficulty intuiting the emotional states of others, and deficits in self- and social-awareness that can impair humor, comprehension of non-literal or affective language, and social judgment (Kaufman et al., 2008). In individuals with DCC and normal general intelligence, the most important neuropsychological consequence of callosal agenesis seems to be deficiencies in abstract reasoning, concept formation, and problem solving. Although scattered results in the literature have suggested problems in psychosocial functioning, this sub-issue has not been explored in depth (Sengenberger-Rosenbery, 2001). The roles of each hemisphere in processing emotional and social information have been difficult to understand.

Neurological evidence has indicated that specific structures link emotional responses and cognition (Paul et al., 2007; Paul, Erickson, Hartman, & Brown, 2016).

**Language Associations**

Individuals with DCC can, in some cases, perform normally on standardized intelligence tests. Nevertheless, recent studies have suggested that individuals with DCC and normal IQ scores have deficits in domains of fluid and social intelligence (Chiappedi & Bejor, 2010). Individuals with ACC perform worse than controls on narrative joke subtests (Brown et al., 2004, p. 906). In this same study, anecdotal reports
from families suggest diminished appreciation of the subtleties of social interactions, and deficits in the comprehension of jokes and stories. In the Paul, Van Lancker-Sidtis, Schieffer, Deitrich, & Brown (2003) tests, the performance of individuals with ACC was similar to patients with right hemisphere brain damage. Thus, persons with ACC appear to lack interhemispheric integration of critical aspects of language processed by the right hemisphere. Furthermore, results of the Paul, Schieffer, and Brown’s (2004) study demonstrated that individuals with complete ACC are impaired in understanding socially complex scenes and generating appropriate narratives.

Language delay and unusual speech are defining features of ASD and are widely reported for individuals with AgCC (Demopoulos, Yu, Paul, Sherr, & Marco, 2015). In addition to speech and language dysfunction, DCC has been associated with difficulty in social interaction, a core symptom for individuals with an ASD diagnosis. The link between atypical sensory processing and corpus callosum abnormalities and autism is not fully understood; however, preliminary evidence suggests that the two are related. As researchers study the corpus callosum (CC), the largest interhemispheric brain connection, they find that it likely plays a pivotal role in all aspects of sensory information processing necessary for the development of language, social skills, and other higher-order cognitive functions. Overall, these findings suggest that abnormalities in the CC may limit the ability of the brain to rapidly integrate the multiple sources of information that contribute to a successful communication or social interaction (Kang, 2008).

Language differences may become more apparent as individuals with DCC move into adulthood. Children with a typical corpus callosum have incomplete myelination of
the corpus callosum. A recent study hypothesized that paralanguage deficits in children with congenital ACC would be less apparent relative to their peers. When controlling for age, children with ACC were significantly poorer in comprehension of the precise meaning of both literal and nonliteral items on The Familiar and Novel Language Comprehension Test (FANL-C). While deficits in paralinguistic, the how something is said and not what is said, processing were apparent, children with ACC were not as clearly different from age peers as adults, and were equally deficient at comprehending literal and nonliteral expressions. Recent research has revealed a greater impaired processing of nonliteral meaning and affective prosody in adults with agenesis of the corpus callosum (ACC) and normal intelligence (Brown et al., 2005, p. 135).

**Cognitive Associations**

Cognitive differences can lead to behavioral differences and language alterations. ACC results in deficits in complex cognitive operations such as reasoning, concept formation, and problem solving. It is suggested that these cognitive deficits may be related to diminished interhemispheric transfer of complex information (Brown, Anderson, Symington, & Paul, 2012). In individuals with ACC and normal general intelligence, the most important neuropsychological consequence of callosal agenesis seems to be deficiencies in abstract reasoning, concept formation, and problem solving. ACC is associated with specific problems in complex cognitive operations (Brown & Paul, 2000; Schieffer, 1999). Results demonstrate that individuals with complete ACC are impaired in understanding socially complex scenes and generating appropriate narratives (Paul, Schieffer, & Brown, 2004). Confabulation was described in a 23-year review by Stickles, Schilmoeller, and Schilmoeller (2002) of an individual with
agenesis of the corpus callosum. The principal was described as “at times confabulating and often telling people what they wanted to hear, rather than the truth” (p. 376). At times the principal used language that was inappropriate for the setting and audience, and he was not aware of listener cues that might inform him that this was occurring. Jeeves and Temple (1987) reported that, among ACC patients who had adequate expressive language skills, meaningless or out-of-place conversation was particularly common.

Cognitive differences in people with DCC may be less pronounced in children and adolescence. A study of two school-age children with normal intelligence and DCC on the mechanisms of interhemispheric transfer and patterns of cognitive function results of visual interhemispheric transfer tasks suggested degradation in transfer of information to the left hemisphere. Results of a tactile interhemispheric transfer task suggested degradation of access to the right hemisphere. No consistent pattern of cognitive deficits was observed. Few, if any, consistent deficits are evident from the data available (Fischer, Ryan, & Dobyns, 1992). Research by Brown and Paul (2000) examined two adolescents with ACC and normal IQs using a battery of cognitive and psychological test. The test results indicated poor interhemispheric integration of complex material. Performance on tests of reasoning and concept formation were clearly below expectations based on IQ. Significantly poor performance also was found on tests of social insight, proverb interpretation, social logic, self perception, and interpretation of ambiguous stimuli. The Brown et al. (2012) study suggests that individuals with ACC have difficulty in inferring game contingencies and forming a
coherent selection strategy, implicating the corpus callosum in these decision processes (p.532). The specific nature of these problems is not yet clearly understood.

Individuals with AgCC performed significantly below healthy controls on the Delayed Memory Factor test, confirmed by significant deficits in short and long delayed free recall and cued recall (Erickson, Paul, & Brown, 2014). They also performed less well in original learning. Deficient performance by individuals with AgCC during learning trials, as well as deficits in all forms of delayed memory, suggest that the corpus callosum facilitates interhemispheric elaboration and encoding of verbal information.

Confabulation

Dalla Barba (1993a) defined confabulation as unintentional verbalization incongruous with the present situation. Traditionally the definition includes (1) false (2) reports (3) about memories (Hirstein, 2009 p. 3). Confabulation can assume many forms. To use a concrete label, the definition of confabulation has proven to be a difficult and controversial topic. Some people are aware of their confabulation and some are not (Hirstein, 2006). Definitions of confabulation can alternately include or exclude delusions and false memories.

Historical Perspective of Confabulation

Confabulation has been associated with many diseases and injuries. It was first associated with Korsakoff patients and cognitively impaired chronic alcoholics (Baddeley, Kopelman, & Wilson, 2004 p. 20). It has since been associated with lesions, psychiatric disorders, post-traumatic stress disorder, traumatic brain injury, and medications (Baddeley et al., 2004, p. 73; Dalla Barba, Boissé, Bartolomeo, & Bachoud-
Confabulation, more recently, is associated with frontal lobe damage (Dayus & Van den Broek, 2000), in particular right frontal lobe damage (Joseph, 1999) and the corpus callosum (Hirstein, 2006, p.3; Pandya & Seltzer, 1986). Benson et al. (1995) suggested the orbital and medial frontal cortex as the mechanism for confabulation. Data from numerous studies are consistent with this suggestion (e.g., Broman, Fletcher, Hannay, & Brandt, 1999; Papagno & Baddeley, 1997).

**Confabulation Classification**

Researchers have classified confabulation under the following subgroups: memory confabulations, confabulations about intentions and actions, perceptual confabulations, and confabulations about emotions (Hirstein, 2009). Assessments for confabulation often break the categories into: spontaneous confabulation, provoked confabulation, and memory and orientation (Rensen et al., 2015; Schnider, 2003). Schnider (2008) argued that historically the authors of research on confabulation fit their categories of different types of confabulation to their observations (p. 54).

The Sacramento Assessment of Confabulation (SAC) was developed to add precision to the description of confabulation and establish whether confabulation can be considered on a continuum. The instrument also was developed as a measure to determine whether individuals who confabulate, with intervention, have a potential for recovery. An additional subtest valued one’s willingness to “not know” (Smith, 2011).

**Rating Scales for Confabulation**

Dalla Barba (1993a, 1993b) measured confabulation quantitatively. He required participants to answer a variety of questions, which required episodic memory and long-
term memory (including memory for famous people and events). Unfortunately, Dalla Barba’s questions were idiosyncratic to French—e.g., French athletes, politicians, and battles.

The Gudjonsson Suggestibility Scales (GSS) and the Bonn Test of Statement Suggestibility (BTSS) are the most used tools for assessing interrogative suggestibility. Apart from minor differences, the two tests investigate the same dimensions: Yield, Shift, Immediate Recall, and Total Suggestibility (Roma, Sabatello, Verrastro, & Ferracuti, 2011). These are used to measure suggestibility and could be used to test provoked confabulations.

Smith (2011) conducted a study to: “a) to determine whether a relationship exists between severity of cognitive impairment and degree of confabulation; and b) to determine a method with which to quantify confabulation” (pp. 22-23). Smith investigated confabulation in people with Traumatic Brain Injury (TBI). Confabulation has a variety of definitions, with Smith testing for discontinuity and unintentional false reporting on general knowledge of personal semantics, memory, orientation in time and place, and general semantic memory. The study was designed to add to the the body of knowledge on TBI and confabulation by quantifying personal semantic memory, general semantic memory, orientation in time, and orientation in place anomalies in recall. One of the objectives in the investigation was to develop a tool to assess confabulation in individuals with TBI.

There were 31 adult participants in Smith's (2011) study with TBI. All individuals in the participant group had TBI from external and not internally induced trauma. All were English language speakers. Data from a control group of 90 typical
young adults also were obtained. A series of 32 questions were asked of the participants and scored on a five-point scale ranging from five being clearly a confabulation to one being assumed accurate. Questions covered personal semantic memory, general semantic memory, orientation in time, and orientation in place. The answers were judged for consistency of measurement with a consistency coefficient of .90. A two tailed $t$ test was calculated to determine whether the variety between groups, control and participant, was greater than the variety within each group. Smith helped to create and then used the Sacramento Assessment of Confabulation (SAC) to assess the general knowledge of personal semantics, memory, orientation in time and place, and general semantic memory of the participants.

Smith’s (2011) analysis revealed a significant relationship between confabulation and level of cognitive functioning in participants with TBI. Those with TBI had higher levels of confabulation on the general and personal semantic memory, and orientation to time and place sections of the SAC test of confabulation than the general population. Smith (2011) noted that some used external cues (e.g., a clock or whiteboard with a schedule on the wall) to help answer the questions. Some of the participants did not exploit these prompts. Some of the rooms had these assets and some did not. The author acknowledges that this is a variable that should be controlled in future studies. The SAC would have to be assessed for appropriateness for use with other populations.

At present the development of instruments to assess level of cognitive functioning and confabulation is in evolution. The SAC used in Smith’s (2011) study
included questions that are date sensitive and would need to be assessed before using with a population in 2016 and beyond. The Krackow and Lynn (2009) study pointed to the difficulties of assessing memory and cognitive function in preschool age children. The Nijmegen-Venray Confabulation List (NVCL-20) is an observation scale to measure spontaneous confabulation. The items on this scale cover spontaneous confabulation, provoked confabulation, and memory and orientation (Rensen et al., 2015). The researchers noted:

The NVCL-20 has been validated in Korsakoff patients and cognitively impaired chronic alcoholics. Their ratings were related to the Dalla Barba Confabulation Battery (DBCB), Provoked Confabulation Test (PCT), and standard neuropsychological tests. The categories of the NVCL-20 have “good” to “excellent” internal consistency and inter-rater agreement. Administration is reliable, valid and feasible in clinical practice, making it a useful addition to existing confabulating measures. (Rensen et al., 2015, p. 804)

As with TBI, the prevalence of confabulation within the community of people with DCC had yet to be quantified. Often confabulation is often assessed by observations, questionnaires, and structured interviews. Researchers are still exploring tools to quantify spontaneous confabulation.

**Special Education for Disorders of the Corpus Callosum**

Our understanding of how to best serve people with DCC educationally is evolving. In 1983 we understood that hemispheric specialization can proceed in the absence of the corpus callosum. There is no good evidence that acallosal brains are any
less laterally specialized than normal ones; thus, there is no compelling reason to argue that hemispheric specialization requires the corpus callosum to have been present in childhood. It is likely that both cognitive and skilled performances suffer as a result of callosal agenesis, although there are great individual differences and the nature of the impairments remains unclear (Milner, 1983). We learned in 1988 that most congenital ACC cases do not display hemi-syndromes or callosal syndromes, similar to surgical acallosals, but they exhibit some deficit in terms of hemispheric integration. It appears that the most common neuropsychological findings in DCC cases relate to deficits in visuo-motor and/or spatial-perceptual functioning (Bigler, Rosenstein, Roman, & Nussbaum, 1988). The Sauerwein and Lassone (1994) study of acallosal and callosotomized school age children and adolescents’ data suggest that the corpus callosum may be important for interhemispheric transfer of tactuo-motor learning when a spatial component is involved. Most acallosals show clear hand preference and hemispheric dominance for the processing of verbal and visuo-spatial information, and their verbal and performance IQ scores do not reveal any imbalance in favor of one or the other.

Further evidence shows that in patients who have had surgical commissurotomy of the corpus callosum, learning and memory are not unitary functions but are multi-component (i.e., encoding, consolidation, retrieval, and recognition) and multi-modal (e.g., auditory, visual, olfactory, and motor) processes that involve a variety of brain regions (e.g., the medial temporal lobe, frontal lobes, cerebellum, amygdala, neocortex, and striatum). Studies of commissurotomy patients have made it clear that each hemisphere is capable of its own memory encoding and retrieval, and that cutting the
cerebral commissures does not prevent basic memory processes, although lateralized differences in the content of memory are present (Reuter-Lorenz, 2003; Saidel, 1990; Zaidel & Sperry, 1974).

Another consideration under study is that the corpus callosum can serve both an inhibitory and excitatory influence on the contralateral hemisphere. Bloom and Hynd (2005) conglomerated several studies that have taken the position that the corpus callosum provides the conduit through which a hemisphere or cortical area can inhibit the other hemisphere or homologous cortical area in order to facilitate optimal functionality. Bloom and Hynd then juxtaposed them with studies that have suggested the corpus callosum integrates information across cerebral hemispheres and thus serves an excitatory function in interhemispheric communication. The available research, no matter how limited, has primarily supported the notion that the corpus callosum serves a predominantly excitatory function. There is evidence, however, to support both theories and the possibility remains that the corpus callosum can serve both an inhibitory and excitatory influence on the contralateral hemisphere.

Two fundamental features of the brain’s functional architecture are a “rich endogenous dynamics” (Raichle et al., 2001) and an “organization of functional networks” (Sporns & Zwi, 2004.) Evidence of neuroplasticity in children show that largely normal functional networks can emerge in brains with dramatically altered structural connectivity. This may be limited to cases in which (1) the structural connectivity abnormality is developmental, permitting substantial functional reorganization early in life; and (2) cognition is largely normal. Perhaps the most profound aspect of the present findings is the suggestion that the functional organization
of the brain subserving cognition can be driven by factors other than direct structural connectivity (Tyszka, Kennedy, Adolphs, & Paul, 2011).

Nevertheless, lack of normal callosal development can lead to deficits in functional connectivity that are related to impairments in specific cognitive domains (Hinkley et al., 2012). Recent findings also suggest two broad conclusions. First, they support the hypothesis that congenital disruption of the corpus callosum constitutes a major risk factor for developing autism. Second, they quantify specific features that distinguish autistic behavior associated with callosal agenesis from autism more generally (Paul, Corsello, Kennedy, & Adolphs, 2014).

In the Badaruddin et al. 2007 study, school age children with ACC (ages 6-11) manifested problems in attention, social function, thought, and somatic complaints. The 6-11 age group also was compared to Child Behavior Checklist (CBCL) data from 52 children with autism who were selected from a previous study. Children with ACC were generally less impaired than children with autism on nearly all scales, with significantly less severe problems in the areas of attention, anxiety/depression, social function, and unusual thoughts. In a further questionnaire related to diagnosis of autism within the domains of social interaction and social communication, children with both autism and ACC manifest difficulties in these domains, but fewer children with ACC manifest repetitive and restricted behaviors.

The Krackow and Lynn (2009) study pointed to the difficulties of assessing memory and cognitive function in preschool age children. The Paul, Erickson, Hartman, and Brown 2016 article presented findings that suggest the corpus callosum facilitates more efficient learning and recall for both verbal and visual information, individuals
with AgCC may benefit from receiving verbal information within semantic context, and
known deficits in facial processing in individuals with AgCC may contribute to their
impairments in recall for faces. Cumulatively across the verbal learning trials with word
pairs, the AgCC group had worse immediate recall than the control group, despite the
fact that both groups recalled a similar degree of incremental improvement with
repetition.

DCC is a relatively rare disorder and therefore has very little educational
referencing (Chiappedi & Bejor, 2010; Jeeves & Temple, 1987). DCC also is a
spectrum disorder. At present it would be best to look at each individual’s strengths
and weaknesses for assessment of educational services.

**Education for Confabulation**

The field of study on confabulation is moving toward the investigation of a
relationship between confabulation and Disorders of the Corpus Callosum. At present
the development of instruments to assess level of cognitive functioning and
confabulation are in evolution. Mitigation or treatment for confabulation is somewhat
dependent upon the cause or source, if identifiable. For example, large doses of vitamin
B is a treatment given to Wernicke–Korsakoff syndrome patients to reverse thiamine
deficiency. General cognitive techniques may be used to treat confabulation. A case
study published in 2000 showed that Self-Monitoring Training (SMT) reduced
delusional confabulations (Dayus & van den Broek, 2000). Further investigations may
inquire whether Event Report Training (ERT) could be a means to decrease rates of
confabulation in people with DCC (Krakow & Lynn, 2009). Although these treatments
seem promising, more rigorous research is necessary to determine the efficacy of SMT and ERT in the general confabulation population.

Krakow and Lynn (2009) evaluated the efficacy of Event Report Training (ERT) when used with preschool and school age children. Their literature review draws attention to the limitations of previous studies and leads directly to their research question: Do structured interviews increase recall at equivalent rates for preschool and school aged children? Their evaluation was designed to study whether ERT could improve detail and information recall, as well as lower suggestibility in pre-school and school age children. Krakow and Lynn broke ERT into two main components—psychoeducational, to improve reliability in narratives, sequencing, and action reports; and suggestibility or provoked confabulation reduction training. The researchers were attempting to determine whether ERT could allow preschool and school-age children to give more information and be more accurate in interrogations. The hypothesis was that children in both groups, preschool and school-age, would be able to recall more information during free recall if they received ERT compared to those who did not receive ERT. The second hypothesis by Krakow and Lynn states that the children in both age groups who received ERT would respond more accurately to leading questions than the control group children who did not receive ERT.

Krakow and Lynn (2009) designed a quasi-experiment to measure the impact of ERT on the target population. The experiment involved creating a setting in which the children took part in a scenario that involved touch. Two weeks were taken off by the participants, then they returned either to take event report training or watch a video if in the control group. Individuals in both groups then participated in a memory interview.
They made it a quantitative study by coding and scoring the data collected. The preschool ERT group had 15 participants, ages 48-70 months, with a mean age of 60 months. The preschool control group had 14 participants, ages 48-70 months, with a mean age of 60 months. The school-age ERT group had 14 participants, ages 84-103 months, with a mean age of 91 months. The school-age control group had 15 participants, ages 84-103 months, with a mean age of 93 months. The individuals who administered the test were highly trained in procedures, and were kept naïve to the topic of the study to prevent bias. The authors had the parents fill out a form on which they indicated whether their children had or did not have learning difficulties. The authors did not report what they did with this information and whether it played any part in the division of the groups.

Answers were transcribed and checked for accuracy. Coding was done independently by one of the authors and an undergraduate assistant, who were both blind to the experimental conditions. A system was set up for each type of answer. Differences were remedied through discussion. Krakow and Lynn (2009) conducted a series of one-way analyses of variance. The first analysis had the interviewer as the independent variable and number of correct ideas recalled as the dependent. The second analysis had the number of correct responses to misleading questions as the dependent. No significant effects of the interviewer were found. These were followed by ANOVAs and planned comparisons based on age (preschool vs. school-age) X training (ERT vs. control). The authors compared the preschool ERT group vs. the control and the school-age ERT group vs. the control. The researchers analyzed by means and standard deviations if there was an age relevance on recall on the open-ended questions.
The analysis of misleading questions was conducted with means and standard deviations by age and training condition. Planned comparisons were performed on the number of correct responses to misleading questions. An analysis of ‘don’t know’ responses was not conducted as the response was not imperative to the hypothesis and seldom used.

The analysis of Krakow and Lynn (2009) revealed age to be the main effect. School-age children who received ERT provided more complete memory reports and more actions regarding the to-be-remembered events than same-aged control participants. ERT increased open-ended recall responses by 32%, and the number of actions by 32% in school-age children. ERT did not increase the amount of inaccurate information recalled in school-age children. The ability of ERT to reduce suggestibility in school-age children could not be determined due to the participants’ cohesively high scores in accuracy toward misleading questions. The pertinent finding with preschool children indicated they did not benefit from the free recall portion of ERT and a reduced suggestibility to misleading questions about bodily touch.

Krakow and Lynn (2009) noted that possible cognitive-developmental limitations of preschool children could affect the design of the study. They emphasized that this study is the first attempt to reduce preschool children’s suggestibility to questions about bodily touch and therefore should be replicated. The authors also stated that, although ERT was designed to increase recall of action and not to increase information about the setting, people, conversation, affective states, and consequences associated with the event, these other event characteristics also were studied. As researchers admit that 5- to 6-year-old children have a tendency to change their answers
during cross-examination, it was recommended that this be a subject for further study. Furthermore, Krackow and Lynn did not definitively state the age ranges, median, and mode of each of the ERT groups and control groups. They stated only the age range of the two groups in general. There are significant cognitive differences in children between the ages of 48 and 70 months. Another shortcoming of the methodology involved the authors not writing how they selected the participants for each group. They stated that the individuals came from the participant pool of the University of Illinois at Urbana-Champaign. This design may have issues with internal validity, as a baseline was not established. Only a treatment and control group were formed for comparison.

The two studies reveal the importance of training personnel who are in the position to work with questioning children as well as adults with cognitive functioning differences. Both studies brought forward the need for accurate cognitive functioning studies in relation to memory testing. Smith’s (2011) study focused on the connection between TBI and Confabulation, whereas Krakow and Lynn (2009) focused on how Event Report Training may improve children’s eyewitness investigations. The intersection of these two studies would be the issues of cognitive functioning in reporting events and disruptions to the reporting process. Traumatic Brain Injury was the disruption in the Smith article with age and training being the disruptions in the Krakow and Lynn report.

Summary

In Smith's (2011) study, adult participants answered questions on the self-devised Sacramento Assessment of Confabulation. The Krakow and Lynn (2009) experiment used Event Report Training to assess whether the training would increase
children’s memory reports. Krakow and Lynn’s experiment involved creating a setting in which the children took part in a scenario that involved touch, were given two weeks off, returned to either take event report training or watch a video, if in the control group, before participating in a memory interview. The Krakow and Lynn experiment had control over the scenarios being recalled. The Smith study was a reporting on general knowledge of personal semantics, memory, orientation in time and place, and general semantic memory via questionnaire.

Both studies spotlight the importance of relating the level of the participants’ cognitive functioning in studies on confabulation. The Smith (2011) study showed trauma as a factor, with the Krackow and Lynn (2009) study showing age to be a factor. Smith’s study revealed that individuals with TBI had a higher incident of confabulating, especially in the areas of personal semantics, memory, orientation in time and place, and general semantic memory compared to the general population. Smith related the importance of developing instrumentation that can quantify confabulations in order to measure effectiveness of treatments. The Krackow and Lynn study indicated that the ERT increased the completeness of memory reports in school-age children over same-aged control participants. The ERT did not prove pertinent in the findings with preschool children. Not only do therapies to diminish confabulation, increase self awareness, and increase episodic memory need to be tested, but the instrumentation for the measurement of quantity and type of confabulations should be specifically developed for the study of the effectiveness of therapies to aid people who confabulate (Roma, Sabatello, Verrastro & Ferracuti, 2011).
CHAPTER III: METHODOLOGY

This study brought together the perceptions of the prevalence and impact of confabulation in people with DCC. The prevalence and significance of confabulation within the community of those with DCC has yet to be fully explored. The goal of this research was to define this possible educational challenge to the DCC community. The perception of the caretakers of individuals with DCC and other involved community members regarding confabulation was collected and explored in accompaniment with the self reporting of those with DCC.

Research Design

This study covered the main research questions proposed.

1. What is the prevalence of confabulation within the community of individuals with DCC?
2. Does age affect rates of confabulation within the population with DCC?
3. Does gender affect rates of confabulation within the population with DCC?
4. Is there a discrepancy between self-reporting of confabulation and incident reporting by others?
5. Has confabulation had an impact on education for the person with DCC?

The research began with exploration and design of a survey that would be appropriate for exploring confabulation in the DCC population. The survey was sent out to individuals with DCC and community who interact with individuals with DCC via a topical listserv group facilitated by the University of Maine, as well as several special interest groups on social media that serve this community. The survey was created on the Western Kentucky University Qualtrics site. This survey asked for demographical
information such as age of the person with DCC, and whether they were self-reporting or reporting on someone they know with a DCC. To prevent participation bias, the survey introduction asked the participants if they were willing to participate in a survey on characteristic traits in people with DCC and not just confabulation. This was done in order not to prejudice the type of participants that are willing to answer the survey. There may be an over-reporting bias for people that have had experience with confabulation to answer a survey on confabulation whereas a better sample of the population could be gleaned from a survey entitled Trait Study of People with Disorders of the Corpus Callosum. The survey was initially conducted online via a weblink uploaded to the target groups. In a second round of distribution, a table was set up at the Disorders of the Corpus Callosum Conference in Chicago on July 22-24, 2016, with availability to the survey in both paper and electronic formats.

The content validity of the Trait Study of People with Disorders of the Corpus Callosum questionnaire was estimated through the use of a Content Validity Index (CVI) on which experts in the area of confabulation and DCC rated the content of the survey instrument for relevance, giving the instrument validity. Cronbach’s Alpha was utilized to estimate the overall reliability of the results (Carmines & Zeller, 1979).

Participants who accepted the request for an additional qualitative interview were then asked for contact information. Interviews for the qualitative portion of the survey occurred July 22-24, 2016, in Chicago, Illinois. A semi-structured interview process was implemented to gather data regarding educational implications of confabulation in persons with DCC. Pseudonyms were assigned to each participant, and to any individuals to whom the participants referred, to protect identities. Interviews
were recorded and typed, and key points and themes were coded, and analyzed. The content was coded by summative content analysis. The main themes were recorded and given weight by summative value (number of times repeated) and essence-capturing (topical about education) in this dissertation.

**Sample**

This study was based on the following assumptions common to basic research.

- Participants willingly took part in the study.
- Participants comprehended the questions asked on the instruments.
- Participants truthfully answered the questions on the instruments.
- Participants were representative of the population.

The population targeted was exclusively adult individuals. Both individuals with a corpus callosum disorder, for self-reporting, and the community that interacts with children and adults with corpus callosum disorders, for second-person accounts and perceptions were invited to participate. It was important to also survey a sample that does and does not have familiarity and experience with confabulation. The sample included individuals with DCC and members of the population reporting on others with DCC.

The first-round questionnaire was distributed to the listserv and social media groups that target people interested in or affected by disorders of the corpus callosum. All participants who answered the survey were asked to certify as being 18 years or older. The subject, the person about whom the survey taker is talking, could have been under 18. For example, a mother may have given information regarding her experiences with a child who has DCC.
**Instrumentation**

The instrumentation was built from previous research in the field of confabulation. The quantitative questions were mostly Likert-type with open-ended inquisition at the end. The survey was an adaption taken directly from the Nijmegen-Venray Confabulation List (Rensen et al., 2015) that has been adjusted for people with DCC and the community that interacts with them. Direct data and cross tabs of specific questions generated data regarding the research questions. Open-ended questions and qualitative interviews allowed for input by the participants, especially educational implications of confabulation on education.

**Procedures/Data Collection**

Data were collected from the first round of the survey given to the listserve and social media group from the Qualtrics survey site. This round of the survey was given a preliminary data analysis on July 5, 2016, which was conducted to allow time for any adjustments to be made to the survey. The survey did not require changes and remained open until July 26, 2016. The second distribution of the same questionnaire survey was available to participants at the conference on corpus callosum disorders in Chicago from July 22-24, 2016. This survey was available in both print and electronic formats, and was closed July 26, 2016. See Table 1: Interview Schedule.

The interviews were scheduled around the participant’s schedule. The place and time of were scheduled according to the comfort of the individual. A private conference room was secured at the venue site where the conference on corpus callosum disorders was taking place for the ease of the participants. At the interview, a letter of consent was signed explaining the confidentiality process, and the pseudonyms were applied.
Interviews were recorded for future reference of the primary researcher and to allow for typed transcripts of the interview for the coding process. Questionnaires, responses, notes, recordings, and scripts are kept in a locked file cabinet in a secure office. These documents will remain locked for five years from the final completion date of the study.

Table 1

*Interview Schedule*

<table>
<thead>
<tr>
<th>What</th>
<th>To whom</th>
<th>When</th>
<th>Follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quantitative questionnaire</td>
<td>Listserve and social media special interest groups.</td>
<td>Upon IRB approval</td>
<td>Close survey on July 26, 2016</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Code interviews and do preliminary analysis by July 15, 2016</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Code interviews by August 15, 2016</td>
</tr>
<tr>
<td>Qualitative survey</td>
<td>Select participants attending the Chicago conference on corpus callosum disorders.</td>
<td>Schedule interviews upon IRB approval Interviews conducted July 22-24, 2016</td>
<td>Code interviews by September 20, 2016</td>
</tr>
<tr>
<td>Analysis</td>
<td></td>
<td></td>
<td>Completed by October 1, 2016</td>
</tr>
</tbody>
</table>

*Data Analysis*

A preliminary analysis of the initial round of the quantitative study was made by July 5, 2016. Special note was made of the open-ended questions to see whether any changes were needed to the qualitative portion of the research; no changes were made. More robust findings emerged from the research through multiple methods of data
collection as well as consistent checking of findings. Multiple methods were employed in order to establish converging lines of evidence and contribute to effective triangulation (Yin, 2010). The presence of qualitative stories from persons associated with DCC exists to better support the quantitative data and served to assist the researcher in finding and crafting the story from all data points. A major advantage of qualitative study is the opportunity to find the unexpected (Weiss, 1998 p. 181).

In the qualitative portion of the research, a master code list was created using a coding process based upon the participants’ answers. Themes were pulled from the interview data and were ranked by relevancy based on repetition by the participants. The themes served to connect the interviews. In order to be considered a theme, data had to prove relevant through the interviews, with considerable mentions in the majority of the interviews.

**Ethical Considerations**

From a content perspective, a few ethical considerations came to the forefront as issues for careful planning and consideration. All parties providing information were required to be over 18, yet the information collected also covered individuals under the age of 18. The participants held an awareness of the project’s general topic, which involved traits in individuals with disorders of the corpus callosum. However, the specific research that ultimately attempted to understand confabulation as it relates to people with disorders of the corpus callosum was not revealed to the questionnaire participants. The topic was introduced as traits related to those with disorders of the corpus callosum so as not to create a bias as to who would be interested in completing the survey. A high regard for participant anonymity and other ethical issues was taken
into consideration from the researcher’s perspective. First, the IRB administration received information as to the purpose of the research, the interview questions, the qualifications for the participants, and overall goals for the use of the findings. Upon gaining approval, all IRB guidelines were followed.
CHAPTER IV: RESULTS

Instrumentation

Provoked confabulations can be researched in various theoretical contexts. Spontaneous confabulations, due to their involuntary nature, cannot be monitored in a laboratory setting. The confabulation assessments produced by Dalla Barba (1993a, 1993b) and The SAC instrumentations are direct tests, e.g., Do you know today’s date? The questionnaire developed for this dissertation, The Trait Study in Persons with Disorders of the Corpus Callosum (DCC), differed from these tests. The Trait Study in Persons with Disorders of the Corpus Callosum (DCC) questionnaire was made less temporally ephemeral by asking the individuals associated with DCC to report on or self-report on incidents, rates, and trait factors associated with confabulation. Rather than seeking to see whether the subject was confabulating in the present, the individual respondents were asked to report, or self-report, if the individual had DCC on incidences, rates, and traits tied to confabulation.

The questionnaire was modeled closely after The Nijmegen-Venray Confabulation List (NVCL-20), which is a confabulation test with scale items that cover spontaneous confabulation, provoked confabulation, and memory and orientation. It was developed to explore confabulation and used with Korsakoff patients and cognitively impaired chronic alcoholics. The closely related Trait Study in Persons with Disorders of the Corpus Callosum (DCC) questionnaire explores incidences of confabulation in persons with disorders of the corpus callosum.
Instrument Content Validity

The content validity of the questionnaire was estimated through the use of the Content Validity Index (CVI), which estimates the overall validity of the instrument by calculating the agreement scores of raters who judge each question for relevance to the overall concept of confabulation. The CVI yields a Kappa statistic for designating overall rater agreement on the relevance of the questions to the understanding of confabulation in persons with a disorder of the corpus callosum.

The CVI involved highly qualified raters to judge each of the 22 questions on the DCC questionnaire as to the relevance to each in the understanding of confabulation in persons with a disorder of the corpus callosum. The raters consisted of two Ph.D. holders who have written on confabulation, an M.D. who is an expert on Disorders of the Corpus Callosum, two registered nurses with experience with people with DCC and confabulations, a Juris Doctor familiar with confabulation, a Doctor of Education familiar with DCC and confabulation, and an author on TBI and confabulation with a Master’s of Physical Therapy. Each of the 22 questions was scored on a 1-4 scale: 1 = Not Relevant, 2 = Somewhat Relevant, 3 = Quite Relevant, 4 = Highly Relevant. Raters provided a single rating for each question.

Once all raters had completed scoring the instrument, the individual values for each rater were entered into the scoring formula recommended by Polit and Beck (2006). The CVI yielded overall Kappa value for the instrument of 1.00, a perfect rating. This showed strong conceptualizations of constructs, good items, and judiciously selected experts (Davis, 1992). This rating indicated the raters were in very high
agreement that the individual questions were highly relevant to the concept of
confabulation (Lynn, 1986; Polit & Beck, 2006; Polit, Beck, & Owens, 2007).

Further, feedback from the experts on the validity of the instrument included:

“Good Differential Diagnosis questions. That should help the treating team
determine how best to manage the client’s care. Nice job.”

“I have rated the questions that tap the core aspects of spontaneous (i.e., ideas
incorrect in time/place, acting upon ideas, content, and the steadfastness of the ideas)
and provoked (i.e., providing incorrect answers in situations in which a person feels
compelled to respond) confabulations as highly relevant. I believe all other questions
are also relevant and contribute to the understanding of confabulations. For example:
Patients might spontaneously confabulate, but not about wrong appointments, visitors
or places (Q5, Q6, Q7). However, because these are common themes of
confabulations, I think they should be included in a confabulation questionnaire. They
might give insight in themes of confabulations in a patient. The same goes for items on
orientation and memory functioning. They do not directly assess confabulations, but
are strongly related to confabulations.”

“Your questions on the questionnaire were all, in my opinion, quite
relevant, and indicative of your having studied this phenomenon well.”

**Instrument Reliability**

The CVI results indicate a strong case for validity of the instrument. The NVCL-20 is an observation scale to measure spontaneous confabulation. This scale's items
cover spontaneous confabulation, provoked confabulation, and memory and orientation.
The NVCL-20 has been validated in Korsakoff patients and cognitively impaired
Respondents

There were a total of 170 respondents to the survey, with 139 surveys mostly completed. All participants were pulled from a social media group and conference directly involved with people with DCC. All respondents were over the age of 18. Data came from family, friends, medical professionals, educational professionals, and other individuals who have associations with the population with DCC. Respondents with DCC could self-report if 18 or older; the associated group could report on an individual under the age of 18. The purpose of this study was not to measure how extensively or
how often persons with DCC confabulate but the percentage of people with DCC who
confabulate and additionally, if confabulation is an educational concern.

As people with DCC may have associated anosognosia, or a deficit in self-
awareness, this study included the perceptions of the individuals with DCC as well as
the community that interacts with them. This study examined frequency and types of
confabulation as a means to understand whether confabulation is a concern for those
with DCC and if it affects education. The perceptions of the DCC community on the
possible connections between confabulation and educational implications were recorded
with the aim of improving the educational experience for people with DCC.

This study covered the main research questions proposed.

1. What is the prevalence of confabulation within the community of individuals
   with DCC?
2. Does age affect rates of confabulation within the population with DCC?
3. Does gender affect rates of confabulation within the population with DCC?
4. Is there a discrepancy between self-reporting of confabulation and incident
   reporting by others?
5. Has confabulation had an impact on education for the person with DCC?

**Research Questions**

**Research Question 1**

What is the prevalence of confabulation within the community of individuals
with DCC? Keeping in mind that the purpose of this study was not to measure how
extensively or how often persons with DCC confabulate but, rather, the percentage of
people with DCC who confabulate; the answers of always, often, sometimes, and rarely
are seen collaboratively as a positive response to this question. The data collected via this survey questionnaire is a measure of spontaneous confabulation, memory, or orientation forms of confabulation, not of provoked confabulation.

Of the 139 respondents, a total of 98 (70.5%) positively affirmed some incidents of spontaneous confabulation. Forty-one individuals (29.5%) responded “never.” Of the responses considered positive for spontaneous confabulation, 31 (22.3%) indicated “rarely,” an additional 45 (32.37%) responded “sometimes,” 17 (12.23%) responded “often,” with 5 (3.6%) indicating “(almost) always” (Table 2).

Table 2

Reported Rate of Confabulation

<table>
<thead>
<tr>
<th>Response</th>
<th>% of Respondents</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>29.50</td>
<td>41</td>
</tr>
<tr>
<td>Rarely</td>
<td>22.30</td>
<td>31</td>
</tr>
<tr>
<td>Sometimes</td>
<td>32.37</td>
<td>45</td>
</tr>
<tr>
<td>Often</td>
<td>12.23</td>
<td>17</td>
</tr>
<tr>
<td>(almost) Always</td>
<td>3.60</td>
<td>5</td>
</tr>
</tbody>
</table>

Research Question 2

Does age affect rates of confabulation within the population with DCC? A cross tab of the 139 responses on age groups and affirmation or negation of reports of confabulation was positive for reports of confabulation across all age levels. There were 52 total responses reporting on persons under the age of 14, 14 ages 14-17, 14 ages 18-20, 19 ages 21-25, 14 ages 26-30, 6 ages 31-35, 9 ages 36-40, 4 ages 41-45, and 6 ages 46 and older. In all age categories, more respondents rated individuals with DCC as
confabulating than not (Table 3). There was a chi-square value of 3.67, with 9 degrees of freedom, and a \( p \) value of 0.93.

Table 3

*Age of Individual with DCC x Reported Rate of Confabulation*

<table>
<thead>
<tr>
<th>Age of individual with DCC</th>
<th>Total number of individuals</th>
<th>Total number of individuals answering “never confabulates”</th>
<th>% of individuals answering “never confabulates”</th>
<th>Total number of individuals answering “sometimes, often, or (almost) always confabulates”</th>
<th>% of individuals answering “sometimes, often, or (almost) always confabulates”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 14</td>
<td>52</td>
<td>19</td>
<td>36.54</td>
<td>33</td>
<td>63.46</td>
</tr>
<tr>
<td>14-17</td>
<td>14</td>
<td>3</td>
<td>21.43</td>
<td>11</td>
<td>78.57</td>
</tr>
<tr>
<td>18-20</td>
<td>14</td>
<td>3</td>
<td>21.43</td>
<td>11</td>
<td>78.57</td>
</tr>
<tr>
<td>21-25</td>
<td>19</td>
<td>5</td>
<td>26.32</td>
<td>14</td>
<td>73.68</td>
</tr>
<tr>
<td>26-30</td>
<td>14</td>
<td>5</td>
<td>35.71</td>
<td>9</td>
<td>64.29</td>
</tr>
<tr>
<td>31-35</td>
<td>6</td>
<td>2</td>
<td>33.33</td>
<td>4</td>
<td>66.67</td>
</tr>
<tr>
<td>36-40</td>
<td>9</td>
<td>2</td>
<td>22.22</td>
<td>7</td>
<td>77.78</td>
</tr>
<tr>
<td>41-45</td>
<td>4</td>
<td>1</td>
<td>25.00</td>
<td>3</td>
<td>75.00</td>
</tr>
<tr>
<td>46+</td>
<td>6</td>
<td>1</td>
<td>16.67</td>
<td>5</td>
<td>83.33</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>0</td>
<td>0.00</td>
<td>1</td>
<td>100.00</td>
</tr>
</tbody>
</table>

**Research Question 3**

Does gender affect rates of confabulation within the population with DCC?

There was a total of 97 responses to gender, with a total of 41 reports on males and 56 on females. A percentage of 17.07 of the reports on males responded “never,” and 82.93% of the reports on males responded positive for incidences of confabulation. Of the reports on females, 19.64% responded “never,” with 80.36% responding positive for incidences of confabulation (see Table 4). There was a chi-square value of 0.10, with 2 degrees of freedom, and a \( p \) value of 0.95.
Table 4

**Gender of Individual with DCC x Confabulation Rate**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>% Never</th>
<th>Rarely, Sometimes, Often, (almost)</th>
<th>% Rarely, Sometimes, Often, (almost)</th>
<th>Total</th>
<th>% Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>7</td>
<td>17.07</td>
<td>34</td>
<td>82.93</td>
<td>41</td>
<td>100.00</td>
</tr>
<tr>
<td>Female</td>
<td>11</td>
<td>19.64</td>
<td>45</td>
<td>80.36</td>
<td>56</td>
<td>100.00</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0.00</td>
<td>0</td>
<td>0.00</td>
<td>0</td>
<td>100.00</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>18.56</td>
<td>79</td>
<td>81.44</td>
<td>97</td>
<td>100.00</td>
</tr>
</tbody>
</table>

**Research Question 4**

Is there a discrepancy between self-reporting of confabulation and incident reporting by others? Of the 139 respondents, 34 were self-reporting and 106 were persons associated with and reporting on an individual with DCC. Of the self-reporting individuals, 32.35% said they “never” confabulate in opposition to the 28.3% of individuals associated with and individual with DCC who answered “never.” Of note is the opposite end of the scale in which 2.94% of individuals with DCC self-reported “often” confabulating, and 15.09% of the persons associated with an individual with DCC reported “often.” Similarly, 0.00% of individuals with DCC self-reported “(almost) always” confabulating and 4.72% of those individuals associated with an individual with DCC reported “(almost) always” confabulating (see Table 5). There was a chi-square value of 6.69, with 4 degrees of freedom, and a $p$ value of 0.15.
Table 5

*Spontaneous Confabulation in Individuals with DCC x Self-Reporting vs. Community Reporting*

<table>
<thead>
<tr>
<th></th>
<th>Self-Reporting</th>
<th>% Self-Reporting</th>
<th>Community Reporting</th>
<th>% Community Reporting</th>
<th>Total</th>
<th>% Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>11</td>
<td>32.35</td>
<td>30</td>
<td>28.30</td>
<td>41</td>
<td>29.50</td>
</tr>
<tr>
<td>Rarely</td>
<td>11</td>
<td>32.35</td>
<td>21</td>
<td>19.81</td>
<td>31</td>
<td>22.30</td>
</tr>
<tr>
<td>Sometimes</td>
<td>11</td>
<td>32.35</td>
<td>34</td>
<td>32.08</td>
<td>45</td>
<td>32.37</td>
</tr>
<tr>
<td>Often</td>
<td>1</td>
<td>2.94</td>
<td>16</td>
<td>15.09</td>
<td>17</td>
<td>12.23</td>
</tr>
<tr>
<td>(almost)</td>
<td>0</td>
<td>0.00</td>
<td>5</td>
<td>4.72</td>
<td>5</td>
<td>3.60</td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>34</td>
<td>100.00</td>
<td>106</td>
<td>100.00</td>
<td>139</td>
<td>100.00</td>
</tr>
</tbody>
</table>

**Research Question 5**

Has confabulation had an impact on education for the person with DCC? The qualitative portion of this research was used to reveal whether there were overarching educational implications of confabulation for individuals with DCC. Interview and focus groups participants discussed their experiences and interpretations of the effects of confabulation on the educational process in individuals with DCC. In five sessions that took place on July 22 and July 23, a total of 10 individuals participated in small group sessions. The central theme of the participants’ accounts brought provoked confabulations to the forefront. All of the participants stated that confabulation had at one time affected the educational setting of the person with DCC. Eighty percent, or 8/10 of the participants, said the person with DCC had been known to spontaneously confabulate in an educational setting. All of the participants gave narratives in which “pressure” and “lack of time” provoked confabulations. When asked how confabulations may be mitigated in an educational setting, all participants conveyed the need for “time,” “time to process,” or “processing time.” Another common suggestion by 50% of
the participants included “better information for the teachers” on school-aged children with DCC.

Analysis for this study was conducted throughout the data collection process while interviewing participants and examining other materials such as conference notes. In accordance with the research questions, the initial themes used for coding were confabulation, age, self-knowledge, and education. During the interview process, the theme of confabulation was further differentiated into spontaneous and provoked. Through repeated analysis of interview transcripts and inductive content analysis, additional themes emerged from the data: processing time and teacher education. The original themes of confabulation, age, self-knowledge, and education were present in the data. The emergent themes of provoked confabulations, processing time, and teacher education generated added depth and additional understanding to the study, as they illuminated areas of the investigation and structure that were not known to be of great importance in the beginning of the study.

When asked what would help people with DCC in an educational setting, “more time” and “processing time” was a unanimous answer. Additional insights included: “If the teacher asked me a question, I would just give an answer. Three minutes later the question would process and I could get it. I needed time.” “I would just answer to answer. I needed more time.” “I guess you could call them provoked confabulations (teacher prompted answers).” “Redacted Name, understands better if you ask the question and then get back to her.”
CHAPTER V: CONCLUSION

The purpose of this investigative study was to examine the interrelationships between people with disorders of the corpus callosum and confabulation, and how confabulations may impact education. The central research question was: What is the prevalence of confabulation within the community of individuals with DCC? and was followed by four research questions: (1) Does age affect rates of confabulation within the population with DCC?; (2) Does gender affect rates of confabulation within the population with DCC?; (3) Is there a discrepancy between self-reporting of confabulation and incident reporting by others?; and (4) Has confabulation had an impact on education for the person with DCC?

Confabulation is a recognized characteristic commonly associated with callosal disorders. Disorders of the Corpus Callosum (DCC), like autism, are a spectrum disorder. Those with DCC have a wide range of intelligences from gifted to intellectually impaired (Sauerwein & Lassonde, 1994). People with average to gifted intelligence and DCC may have subtle differences in the way they perceive and react (Chiappedi & Bejor, 2010). A person with a typical IQ and DCC could have episodes of confabulation that may have many personal, educational, and legal implications. This study was designed to explore the prevalence of confabulation within the community of people with DCC, which has yet to be quantified, and possible educational impacts.

Discussion of the Findings

The five research questions emerged as the author read, reviewed, and analyzed the literature. The questions are the driving strength of the study. It was the researcher’s goal to identify knowledge on the intersection of DCC and confabulation, and the
educational impacts. The answers to the first four research questions were explored and uncovered with the data from the quantitative survey. Confabulation is a valid concern within the spectrum of people with DCC. Within the spectrum of those with DCC, persons of all ages confabulate, both males and females confabulate, and some individuals may have issues of self awareness regarding their behavior and confabulation.

The qualitative questions were constructed to promote conversation and the exchange of ideas in order for the participants to feel relaxed enough to discuss their beliefs about DCC, confabulation, and the possible educational impacts of confabulation. This tool opened the discussion to evoke rich, detailed feedback from the participants, who brought forth the outline of “provoked confabulation” and “processing time” as main themes related to DCC, confabulation, and educational impacts.

**Findings Related to the Literature**

The bodies of knowledge on DCC and confabulation are rapidly growing with improved technologies and diagnoses, as well as development of survey instruments. The role age plays in training gains may be further complicated by the type of corpus callosum disorder (Wolf et al., 2014). A conscientious review of the literature revealed a void in knowledge on the intersection of DCC, confabulation, and education. All of these research topics are emerging.

This investigation was a foundational examination that brought together the intersection of DCC and confabulation, and educational impacts. People with DCC have a variety of physical, behavioral, cognitive, and language differences. The literature review and the results of this study show that many individuals with DCC
confabulate. As of yet, the community of people associated with DCC does not have a clear path of best practices to mitigate confabulation in the educational setting. Therapies to mitigate confabulations is a newly emerging field. The results reported in this research directly point to a need to open the door for further research.

**Implications**

The participants in this study and the DCC community can be assured that protection of their interests is preserved. It is the role of the researcher and reader to watch for bias and conflict of interest; of course, any study can be misused intentionally or unintentionally. The purpose of this study was to investigate whether people with DCC have educational implications associated with confabulation in order to facilitate awareness and to start a discussion on possible resources and therapies. Persons with DCC should not be placed under an untenable label as confabulators. It should be emphasized that 29.5% responded “never” to the question: Does the person with the Disorder of the Corpus Callosum (DCC) confabulate spontaneously (on their own without prompting)? Also, of note was the personal stories that related provoked confabulation as a main concern in the educational setting rather than spontaneous confabulation, with “processing time” suggested as a mitigating factor (Marco et al., 2012).

**Limitations**

Schilmoeller and Schlimoeller (2001) reported on their survey of 1,900 families who had a member with DCC. They found differences, mostly delays, in physical milestones, developmental milestones, and social behavior. However, the disorder of the corpus callosum may not be the main cause of the cognitive impairments seen in
many of these cases. Also, although a proportion of those with DCC in the literature review fell in the high to superior range of mental abilities, it should be kept in mind that acallosal individuals with normal intelligence rarely come to the attention of the clinician.

**Recommendations for Future Research**

The research contained herein is foundational. Duplication of this study, as well as further research into provoked confabulations, is recommended. Further long-term, longitudinal studies on treatment methodologies and outcomes for confabulation would allow for best practices regarding education and treatment strategies.
REFERENCES


APPENDIX A: IRB APPROVAL

DATE: July 12, 2016
TO: Cheryl Wright
FROM: Western Kentucky University (WKU) IRB
PROJECT TITLE: [892964-1] Survey of Reported Rates of Confabulation in Persons With Disorders of the Corpus Callosum
REFERENCE #: IRB 17-006
SUBMISSION TYPE: New Project
ACTION: APPROVED
APPROVAL DATE: July 12, 2016
EXPIRATION DATE: December 1, 2018
REVIEW TYPE: Expedited Review

Thank you for your submission of New Project materials for this project. The Western Kentucky University (WKU) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of December 1, 2018.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Paul Mooney at (270) 745-2129 or irb@wk.edu. Please include your project title and reference number in all correspondence with this committee.
INFORMED CONSENT DOCUMENT

Project Title: Survey of Reported Rates of Confabulation in Persons with Disorders of the Corpus Callosum

Investigator: Cheryl L. Wright

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.

You must be 18 years old or older to participate in this research study.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have.

If you then decide to participate in the project, please sign this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

1. Nature and Purpose of the Project:
The corpus callosum is the largest bundle of nerve fibers in the brain. It forms the connections between the right and left hemispheres of the brain. When someone has a condition where the corpus callosum did not develop in a typical manner they are said to have a disorder of the corpus callosum.

Confabulation, communicating information that is untrue while perceiving that it is true, is among the list of possible challenges for people with Disorders of the Corpus Callosum (DCC). People with DCC may have subtle differences in the way they perceive and react. The prevalence and significance of confabulation within the community of people with DCC has yet to be fully explored. This research attempts to begin data collection on the topic.

2. Explanation of Procedures:
Participants are asked to complete the 10 minute survey and then share and participate in a 45 minute private focus group about DCC and confabulation. A mixed group of people with a DCC, friends, family, and professionals will be encouraged to participate.

3. Discomfort and Risks:
There are no known risks to the subjects.

4. Benefits:
The prevalence and significance of confabulation within the community of people with DCC has yet to be fully explored. The goal of this research is to help define this possible challenge to the DCC community.
5. **Confidentiality:**
All data will be coded. No use of actual names or identifying information will be disclosed. All forms, recordings, data, and other information will be kept in a secure manner.

6. **Refusal/Withdrawal:**
Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

    You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

______________________________  __________________
Signature of Participant        Date

______________________________  __________________
Witness                         Date

- I agree to the audio/video recording of the research. **(Initial here)**

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY INSTITUTIONAL REVIEW BOARD
Paul Mooney, Human Protections Administrator
TELEPHONE: (270) 745-2129

WKU IRB# 17-006
Approval - 7/12/2016
End Date - 12/1/2016
Expedited
Original - 7/12/2016
APPENDIX C:

PERMISSION TO ADMINISTER THE QUESTIONNAIRE

Re: NODCC

Guilbault, Robert < >
Mon 7/18/2016 7:59 AM
To: Wright, Cheryl, L < >:

To Cheryl Wright,

Please let this email serve as your approval to work with the NODCC for data collection. This data collection will be done before and during and after the NODCC conference July 2016.

Paul Guilbault, MD
Scientific Advisory Board and NODCC Board of Directors

On Jul 13, 2016, at 5:29 PM, Wright, Cheryl, L < _______@_______.______ > wrote:

Barbara,
I was wondering if the letter that I attached was ok?

Cheryl Wright

________@_______.______
(____) ______

From: Wright, Cheryl, L
Sent: Monday, July 11, 2016 10:14:51 PM
To: NODCC Administration
Cc: Paul Guilbault
Subject: Re: NODCC

Barbara,

For compliance with my review board for my dissertation I need to have a verifiable letter of cooperation (from the NODCC Administration for the conference) to submit for my IRB application. This can be an email. Something simple stating that I have permission to conduct research during the conference. I must have this letter before any data collection can begin including the questionnaire I’d like to send out.

I will be abiding by all IRB protocols for the study including full consent and confidentiality.
Thank you so much!
Any questions please call me at

Cheryl Wright

________@_______.______
(____) ______

From: Wright, Cheryl, L
APPENDIX D:

TRAIT STUDY QUESTIONNAIRE

This study is exploring incidences of confabulation in persons with Disorders of the Corpus Callosum (DCC). Please answer this questionnaire about one person. Confabulation can be defined as communicating information that is untrue while perceiving that it is true. There are 30 questions. If at any time you would like to stop this survey, you can.

Trait Study in Persons with Disorders of the Corpus Callosum (DCC)

Q1. INFORMED CONSENT DOCUMENT

Project Title: Survey of Reported Rates of Confabulation in Persons with Disorders of the Corpus Callosum
Investigator: Cheryl L. Wright

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.

You must be 18 years old or older to participate in this research study.

1. Nature and Purpose of the Project:
The corpus callosum is the largest bundle of nerve fibers in the brain. It forms the connections between the right and left hemispheres of the brain. When someone has a condition where the corpus callosum did not develop in a typical manner they are said to have a disorder of the corpus callosum.

Confabulation, communicating information that is untrue while perceiving that it is true, is among the list of possible challenges for people with Disorders of the Corpus Callosum (DCC). People with DCC may have subtle differences in the way they perceive and react. The prevalence and significance of confabulation within the community of people with DCC has yet to be fully explored. This research attempts to begin data collection on the topic.

2. Explanation of Procedures:
Participants are asked to complete the 15 minute survey. A mixed group of people with a DCC, friends, family, and professionals will be encouraged to participate.

3. Discomfort and Risks:
There are no known risks to the subjects.

4. Benefits:
The prevalence and significance of confabulation within the community of people with DCC has yet to be fully explored. The goal of this research is to help define this possible challenge to the DCC community.

This survey has 30 questions and should take about 15 minutes to complete.

Q2. I am 18 years old or older.

☐ Yes

☐ No. Thank you for your time. Please end this survey.

Q3. Please only answer this survey about one person.

How do you know the person with a Disorder of the Corpus Callosum (DCC)? (Pick as many as apply.)

☐ Self. (I have a Disorder of the Corpus Callosum, and am answering this survey about myself.)

☐ Family Member. (The person with the Disorder of the Corpus Callosum is someone in my family.)

☐ Friend.

☐ Teacher. (I am a teacher for someone with a Disorder of the Corpus Callosum.)

☐ Medical Professional.
Q4. Age of person with the Disorder of the Corpus Callosum.

- Under 14
- 14-17 years old
- 18-20 years old
- 21-25 years old
- 26-30 years old
- 31-35 years old
- 36-40 years old
- 41-45 years old
- 46+
- Unknown. Please provide approximate age

Q5. Confabulation can be defined as communicating information that is untrue while perceiving that it is true. Does the person with the Disorder of the Corpus Callosum (DCC) confabulate spontaneously (on their own without prompting)?

- Never
- Rarely
- Sometimes
- Often
- (almost) Always

Q6. Does (s)he spontaneously tell stories that are incorrect with respect to time and/or place?

- Never
- Rarely
- Sometimes
- Often
- (almost) Always

Q7. How often does the person with DCC spontaneously confabulate?

- Rarely to never
- A few times a week
- Almost every day
Q8. Is the content of the confabulations realistic? Would someone who does not know the person with DCC believe him/her? (An example of realistic, the person wants to go out to work. Not realistic, the person tells you that (s)he has a meeting with the Queen?)

- The stories are realistic (if the context is not being taken into account)
- Some elements of the story do not seem to be plausible
- An outsider would have doubts about the truth of the story (meeting a famous person, being very rich)
- It is obvious that some elements of the story cannot be true
- The stories are very hard to believe

Q9. Does the person with DCC tell you or others that (s)he has an appointment with others (family, doctor) when this is not the case?

- Never
- Rarely
- Sometimes
- Often
- (almost) Always

Q10. Does the person with DCC tell you or others that (s)he had visitors who in fact never visited him/her?

- Never
- Rarely
- Sometimes
- Often
- (almost) Always

Q11. Does the person with DCC believe to be somewhere else other than where (s)he actually is?

- Never
- Rarely
- Sometimes
- Often
- (almost) Always

Q12. Are the confabulations coherent stories, or are they difficult to follow and highly associative?
Q13
Can the person be corrected when telling these stories?

☐ Yes, the person immediately assumes that (s)he is incorrect
☐ Yes, it only takes a little persuasion to convince the person that (s)he is mistaken
☐ Sometimes, the person occasionally sticks to his/her conviction
☐ Usually not, only confronting him/her with the incorrectness of a story results in reconsideration (e.g., an outside temperature of 25°C when the patient states that it is winter)
☐ Usually not, only confronting him/her with the incorrectness of a story results in reconsideration (e.g., an outside temperature of 80°F when the person states that it is winter)
☐ No, the person cannot be convinced of the reality and reacts negatively on efforts to do so

Q14
Does the person recognize acquaintances correctly?

☐ Yes, always
☐ Often
☐ Sometimes
☐ Rarely
☐ No, never

Q15
Does the person show incorrect familiarity ('recognize' strangers, or mistake people for someone else)?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ (almost) Always

Q16
Does the person see or hear things that are not present?

☐ Never
☐ Rarely
Q17. When the person is being asked about what (s)he is presently doing, does (s)he respond correctly?
- Yes, always: the person responds correctly to where (s)he is and why
- Often
- Sometimes
- Rarely
- No, never: the person does not know where (s)he is and why

Q18. When the person is being asked what (s)he did yesterday, does (s)he answer correctly?
- Yes, always
- Often
- Sometimes
- Rarely
- No, never

Q19. When the person is being asked about plans for the day or the next weekend, does the person answer correctly?
- Yes, always
- Often
- Sometimes
- Rarely
- No, never

Q20. When the person is being asked about something (s)he does not remember anymore, (s)he admit this?
- Yes, always
- Often
- Sometimes
- Rarely
- No, never

Q21. Does the person act upon his/her confabulations? Does (s)he for example walk to the door to wait for somebody
or does (s)he get up during a conversation to take care of the dog?

- Never
- Rarely
- Sometimes
- Often
- (almost) Always

Q22. How often does the person act or want to act upon the confabulations?

- Rarely to never
- A few times a week
- Almost daily
- Several times per day
- This happens almost continuously

Q23. Is the person well oriented to place?

- Yes, the person can correctly name the name and location of where (s)he is
- Fairly, the person is usually able to correctly tell where (s)he is
- So-so, the person cannot always correctly provide the location name and place
- Poorly, the person cannot correctly tell where (s)he is and often thinks (s)he is somewhere else
- Very poorly, the person is convinced to be somewhere else

Q24. Is the person well oriented to calendar dates?

- Yes, the person can correctly name the date and year
- Fairly, the person is sometimes one day wrong
- So-so, the person can tell the month and year but not the date
- Poorly, the person can tell which season it is, but not the date of month
- Very poorly, the person cannot name the date and is often several months or years off

Q25. Is the person well oriented to time?

- Yes, the person can correctly tell and keep time
- Fairly, the person can read a clock but can not predict the time
- So-so, the person can understand appointment times but can not keep track of the passage of time
- Poorly, the person does not understand appointment times but understands the need to be on time
- Very poorly, the person does not have a concept of time
Q26. Is the person capable of remembering things, such as names of other people or appointments?
- Yes, (s)he can do this with out problems
- Fairly, it is sometimes necessary to repeat things
- So-so, information must be presented several times
- Poorly, only names of people which (s)he is in frequent contact will be remembered
- Very Poorly the person does not see to profit from repetition and names of other people are not remembered

Q27. Is the person with DCC
- Male
- Female
- Other

Q28. Please provide your email address (Used to prevent duplication only. Your information will not be shared.)

Q29. OPTIONAL QUESTION
Further Comments

Q30. OPTIONAL QUESTION
The person with the Disorder of the Corpus Callosum Disorder. (You may choose more than one.)
- (ACC) Agenesis of the corpus callosum: All or a portion of the corpus callosum is absent; this includes both complete and partial ACC
- (AgCC) Agenesis of the corpus callosum: All or a portion of the corpus callosum is absent. This acronym has appeared more recently in some research literature.
- (c-ACC) Complete agenesis of the corpus callosum: The corpus callosum is completely absent.
- (p-ACC) Partial agenesis of the corpus callosum: A portion of the corpus callosum is absent; most often it is the posterior (back) portion that is missing.
- Hypogenesis of the corpus callosum: Another term sometimes used to describe partial ACC.
- Hypoplasia of the corpus callosum: The corpus callosum is present, but is abnormally thin.
- Dysgenesis of the corpus callosum: The corpus callosum is present but is malformed in some way; this includes p-ACC and Hypoplasia.
- Unknown or Other

Q31. OPTIONAL QUESTION
Does the person with DCC have other health or behavior concerns? Please list.